324 The cystic fibrosis annual review – a need to update the guidance?

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Introduction: CF care requires the monitoring and treatment of a number of organ systems. To aid this, a detailed assessment of all aspects of the CF patient's condition (the annual review, AR) is recommended, but published guidance is 9 years old. The AR content in our adult unit has evolved considerably over recent years. We wished to assess AR use in the UK with a view to informing best practice.
Method: We surveyed 43 specialist CF centres (18 adult, 25 paediatric) about their AR practice.
Results: The AR is supervised by a CF specialist nurse in 21 centres (49%) and a consultant in 17 (39%), usually timed around the patient's birthday. 27 (63%) hold a specific AR clinic. All centres perform full blood count, renal and liver function tests, vitamin assays, spirometry and a chest X-ray: other elements are shown in the Table. Only half of ARs are discussed at a specific MDT meeting, with a report generated in 13 adult (72%) and 23 (92%) paediatric centres.

Annual Review investigations

Investigation performed	Adult units (n = 18)	Paediatric units (n = 25)	χ^2	p
CXR – Northern Score	6	21	11.49	<0.01
Abdominal USS	11	25	11.61	<0.01
Arterial blood gases	4	0	6.12	<0.02
Urine dipstick	2	8	2.55	NS
HBA1c	15	21	0.003	NS
Sputum analysis	18	23	1.51	NS
Immunoglobulins	11	22	4.23	<0.05
Aspergillus serology	17	23	0.09	NS
Pseudomonas serology	12	12	1.47	NS

Conclusion: AR practice in the UK is variable, and there are differences between the adult and paediatric sectors. There is a need to develop specific AR guidelines for adult and paediatric centres in order to standardise the process.

325 What role do the general practitioners (GP) have in the care of cystic fibrosis (CF) patients?

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Introduction: Although the majority of care for CF patients is provided by specialist CF units, GPs can play a vital role in their overall holistic care. The aim of this study was to identify the various aspects of GPs involvement in the care of adult CF patients.
Methods: Using a structured questionnaire, we surveyed 92 consecutive patients (mean age 28 yrs [range 18–66], 45 female) attending our large adult unit, asking about contact with their GP in the previous year.
Results: Although 4 patients never visited their GP, 54% visited 1–2 times, 27% 3–5 times, 7% 6–10 times, and 8% more frequently in the last one year. The commonest reason (28%) was to obtain repeat prescriptions followed by coughs/colds (22%), vaccination (9%), psychological issues (5%), contraception (5%), skin (5%) and musculoskeletal problems (5%) and cervical smear (4%). Other reasons include abdominal, ear and eye problems and UTI. Common medications given by GP were contraceptives, antibiotics, antidepressants, supplements and analgesics. When GP started treatment for respiratory infections, follow-up was planned for only 50%. 75% found it easy to get back-up antibiotics from their GP when needed and 79% would contact the GP first for a non-CF problem. On a scale of 1 (poor) to 10 (excellent) the average GP rating was 7.71.
Conclusion: Although our cohort of CF patients has a variable degree of interaction with their GPs, their overall satisfaction was good. GPs have a vital role in the monitoring of progress, contraception, vaccination, and general health education for CF patients and can provide additional support to the CF team through regular feedback, including compliance issues.

326* Incidence and resource utilisation of pulmonary exacerbations (PE) in patients with cystic fibrosis (CF) in the UK

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Objective: To obtain incidence and resource utilisation data for pulmonary exacerbations (PE) in adult patients with CF and chronic *PA* infections.
Methods: A 1 year retrospective chart review in 5 UK hospitals.
Results: Data was collected on 94 patients, 51% male, mean (SD): age 28.5 (8.2) yrs; FEV_1 58.7 (26.8) %. The mean no. of exacerbations (either requiring hospitalisation or treated at home) per patient per year was 3.6. The mean rate of hospital exacerbations was 1.5 per patient per year and the mean rate of home treated exacerbations was 2.2 per patient per year. Over half (57%) of patients had at least 1 exacerbation requiring hospitalisation. 83% of patients had home-treated exacerbations, with 21% of patients having 1 PE and 62% having multiple PEs. For the 150 hospital PEs the mean length of stay was 9.2 days per exacerbation. Half of the stays required home use of intravenous antibiotics (IVAB) after discharge and almost all (95%) required oral antibiotics. In the 217 home-treated exacerbations nearly half of the exacerbations (42%) required IVABs and 71% oral antibiotics. The mean length of IVAB treatment was 7.6 days per exacerbation and the mean length of oral antibiotics was 10 days per exacerbation.
Conclusion: Pulmonary exacerbations in CF patients with chronic *PA* infection are resource-intensive with over 50% of patients hospitalised per annum in the study.
This study was supported by Novartis and preliminary results were presented at the ERS 2010.

327 An exploration of UK cystic fibrosis nurse specialists' current practice in discussing end of life issues with patients

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Despite advances in management and treatment people with cystic fibrosis (CF) still die at a relatively young age. Although an integral part of the CF multidisciplinary team's workload is palliative care, relatively little is known about the end of life (EOL) issues associated with CF in the UK. Because of the unique circumstances of CF it is not possible to translate findings from other life threatening conditions. I have conducted a study of CF Nurse Specialists (CFNS) in the UK to explore CF EOL issues in the UK.
This was a qualitative study, comprising a questionnaire to all UK CFNS's working within adult centres. 31 UK CFNS's completed a questionnaire (45% response rate). The median time in post for respondents was 7 years.
The findings of this study have highlighted a number of issues. The study reinforces findings from previous studies stating that EOL in CF is varied and complex, especially when the possibility of potential lung transplantation is involved.
Although all respondents felt that early and well-planned EOL discussions were preferable, only 35% of centres had a planned approach with patients. In 10% of situations, EOL was not discussed at all and in 32% of situations, it was not broached until the terminal stage of life. In 94% of situations, the consultant or CFNS raised EOL issues.
68% of respondents had not had any specific training in EOL issues in CF and this is an area that needs to be addressed.
Finally, EOL discussions need to occur on an individual basis, with the patient's needs and wishes respected at all time. Further research in this area, including studies involving patients themselves, is recommended.